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2   Title: Internalising 'Sensitivity': Vulnerability, Reflexivity and Death Research(ers)

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1 **Internalising 'Sensitivity': Vulnerability, Reflexivity and Death**

2 **Research(ers)**

3

4 **Abstract**

5 Research about dying is viewed as inherently sensitive because of how death is perceived in

6 many societies. Such framing assumes participants are 'vulnerable' and sharpens the focus of

7 funders, reviewers, researchers and the public on the potential for 'harm'. At the same time,

8 with increasing recognition of the importance of reflexivity, researchers can become (deeply)

9 preoccupied with their actions and experiences in the field. Whilst reflexivity is often

10 described as a helpful process, in this paper we consider when introspection becomes

11 problematic and even harmful for death researchers, in both a professional and personal

12 sense. Identifying a process we call 'internalising sensitivity' the paper describes our own

13 experiences of working *and* living with the pervasive ethical notions of sensitivity,

14 vulnerability, risk and harm. We argue that these discourses can get 'under the skin' of

15 researchers in that they impact researchers intellectually, emotionally, and physically, and

16 this in turns affects their relationship with the research process and their place within, and

17 beyond it.

18

19 **Key words:** ethics, vulnerability, reflexivity, sensitive research, death studies

20

21 **Introduction**

22   'Much has been said on what the researchers must do to avoid harming participants

23   in the social science literature, but less is written of the potential risk of harms for the

24   researcher who studies sensitive topics and uses sensitive methods' (de Laine

25   2000:75).

26

27 The starting point for this paper is that, whilst much has been written about conducting

28 'sensitive research' with some explicit focus on the topics of death and dying (Goodrum and

29 Keys, 2007; Mckenzie *et al.*, 2017), there is still limited discussion about the impact this has

30 on the death researcher (Woodthorpe, 2007; Visser, 2016; Borgstrom and Ellis, 2017; Burles,

31 2017). In this paper, we unpack how framing death research as *inherently sensitive*, and

1   therefore involving *vulnerable* participants and requiring the use of reflexive approaches, can

2   lead to experiences of uncertainty, vulnerability, and harm for the researcher. By sharing our

3   own experiences (of death research), we seek to expand theorisations of researcher

4   vulnerability, beyond the primary discussions about personal safety and emotionality, to

5   examine how the ethical discourses we operate within, and our reflexive attempts to navigate

6   these, might contribute to our own vulnerability as researchers.

7

8   As scholars working in death-related contexts we recognise that our research is framed by

9   other researchers, ethics committees and funders as inherently 'sensitive' (Addington-Hall,

10 2002). This very idea is deeply pervasive in encounters we have about our work. For instance,

11 when we identify ourselves as death researchers, when we notice how similar research is

12 discussed in academic literature and at conferences, and in particular when we have to

13 navigate through the various concerns of ethics committees. Because of these assumptions,

14 the participants in our research are considered de facto 'vulnerable' and at risk of potential

15 harm. Whilst this is not uncommon in projects deemed to be 'sensitive' (Lee, 1993), it does

16 not adequately represent how we view our research and its participants: these are not the

17 ontological assumptions that we make about studying the end of life.

18

19 As social scientists, we are also aware of how discourses are constructed and shape the

20 realities in which we can operate (Hacking, 1999). Indeed, scholars have begun to challenge

21 assumptions about 'sensitive research' arguing these can be reifying and stigmatising for

22 participants, and (to a limited extent) researchers (Lee, 1993; Liamputtong, 2007). In this

23 paper, we extend these critical discussions in a novel direction by examining how the

24 discursive construction of sensitivity, which draws extensively on ethical notions of risk,

25 vulnerability and harm, can affect the researcher, and in turn, the research they produce. The

26 first section of the paper discusses this discursive context. Then, through reflexive analysis of

27 personal examples, we show how these ideas are internalised by researchers and can feel

28 weighty in intellectual, emotional, and embodied ways. We refer to these feelings as

29 'internalising sensitivity' and our examples explore the effects of this on academic and

30 personal life. The final section problematises the assumption that reflexivity is inherently and

31 always beneficial when doing sensitive research. The wider salience of our observations for

1 researchers doing 'sensitive' work and 'practicing' reflexivity both within and beyond death

2 studies is also considered.

3

4 **Background**

5 **'Sensitive' death studies and its 'vulnerable' participants**

6 There are some topics that are presumed intrinsically 'sensitive' to study (Lee 1993; Sieber

7 and Stanely 1988). Death in England (and in many other countries) is an obvious example.

8 Although researchers have critiqued the label of 'sensitive research' for several decades now

9 (Lee, 1993; Dickson-Swift *et al.*, 2007), work related to death, dying, and end-of-life care is

10 frequently categorised as sensitive in funding proposals, ethics applications, publications, and

11 presentations. We suggest these generalised ideas about sensitivity derive in part from a

12 negative, problems-based view of death and dying (Kellehear, 2009). Often when people talk

13 about death research as sensitive, they do so in general terms rather than stating explicitly

14 *what* makes it so. As Lee and Renzetti (1990) note, the term 'sensitive topic' is frequently

15 used in a common-sense way without being defined. When concerns are articulated they

16 tend to centre upon death's emotionality (Cook and Bosley, 2007; Cain, 2012), or the fact that

17 dying participants have limited, 'precious' time (Barnett, 2001) and reduced capacity to

18 consent due to illness (Gysels *et al.*, 2013). Death (and talking about it) is also considered

19 'taboo' in many countries (Lee, 2008). Even if sociological literature has problematized this

20 idea (Kellehear, 1984), the label 'sensitive' may reflect generalised anxiety about a perceived

21 social stigma associated with death. It points to an academic narrative about doing death

22 research, which draws on societal discourses and expectations about what studying death 'is

23 like', even if existing research literature speaks to a more nuanced way of understanding the

24 field.

25

26 Moreover, it is not uncommon for the terms 'sensitive' and 'vulnerable' to be used

27 interchangeably to describe death research, or other topics deemed to be 'sensitive'

28 (Liamputtong, 2007). Since it is presumed this research is 'sensitive', there is a logical

29 extension that its (human) subjects are essentially 'vulnerable'. For example, ethics

30 committees are frequently concerned about how researchers will manage and respond to

31 participants' emotions during an interview (Borgstrom, 2018). The most common

presumption is that talking about death will upset participants; and although it is not unreasonable to have this concern, informal discussions with members of ethics committees indicate that similar fears may not always be extended with quite such apprehension to other kinds of 'sensitive' research topics. This vulnerability – or potential to cause 'harm' by initialising 'upsetting' conversations – is framed as a 'risk' inherent in this kind of research and something that *responsible* researchers are expected to mitigate and manage.

Vulnerability as problematic for research

Following the 'reflexive turn' in the social sciences, researcher emotions have, to some extent, become a focus of analysis (Parvez, 2018). Less attention has been paid to researcher *vulnerability* specifically and the methodological implications of this. This is despite those who research 'sensitive topics' feeling personally stigmatised by the 'taint' of their area of study (Hockey, 2007). Researchers can also be exposed to risks presented by their research methods (Blackman, 2007) and a burgeoning literature testifies that they experience a range of challenging emotions engendered by their work (Hubbard, Backett-Milburn and Kemmer, 2001; Woodthorpe, 2007; Fincham, Scourfield and Langer, 2008; Woodby *et al.*, 2011). It is now recognised that these feelings can in turn shape the data researchers generate, the course of their analysis (Mauthner and Doucet, 2003) and any subsequent conclusions they make (DeLuca and Maddox, 2016). Yet, often researchers are expected to conceal, deny, or demonstrate how they will minimise their vulnerability. Since consciousness of vulnerability can permeate the researcher's interactions with their participants, one's own vulnerability is considered an impediment to access and data collection (de Laine, 2000). Vulnerability of both participants and of researchers is therefore often framed in the research literature as problematic for the wider research endeavour as well as for individuals. Even in disciplines which seek to foreground human experience, such as anthropology, acknowledging and exposing the vulnerability of the researcher can be difficult and problematic for the research process, and one's career (Behar, 1996; Visser, 2016).

In procedural ethics (Guillemin and Gillam, 2004), the vulnerability of participants and the *safety* (rarely 'vulnerability') of researchers is also deemed problematic by committees tasked with ensuring all research has ethical approval and adheres to strict protocols. The committees and their documentary processes are essentially concerned with identifying risk

1   - the likelihood and extremity of which is considered greater in 'sensitive' contexts where

2   participants are understood to be more vulnerable. Thus, the underpinning rationale for

3   ethical governance is the procedural avoidance of harm caused by research studies and

4   indeed, by extension, the people carrying out this work. Its association with harm and also

5   exploitation means that vulnerability is largely considered as a negative thing and something

6   to be avoided, mitigated and managed.

7

8   By means of its processes of formalisation, procedural ethics also gives the impression that

9   issues like 'sensitivity' and 'vulnerability' can be rendered 'knowable'. It implies that many

10   potential risks, harms and uncertainties can be managed in linear, foreseeable ways via the

11   spelling out of protocol, delineation of categories and rarefication of the research process

12   (Van den Hoonaard and Hamilton, 2016; Sleeboom-Faulkner and McMurrary, 2018). Although

13   some researchers have been critical of the excessive and inappropriate application of notions

14   of 'harm' from biomedical science to research in the social sciences (Haggerty, 2004; Dingwall,

15   2006; Burr and Reynolds, 2010), these ideas have been exponentially pervasive and have

16   significantly shifted attitudes towards the regulation of all research involving human

17   participants. This places a weight of responsibility on researchers to be able to *operationalise*

18   discourses such as sensitivity – to turn these ideas into knowable quantities, situations and

19   scenarios in the context of their proposed work. They are required to make (convincing) plans

20   for how they will eliminate or at least significantly reduce the likelihood that 'bad', unethical

21   things will happen. By extension, this process can feel like a personal measure of the

22   robustness of one's own moral sensibilities. Frequently within death studies, reflexivity is

23   cited as a methodological tool that can be deployed for negotiating these issues (Visser,

24   2016). And whilst this has led to a useful recognition of the possibilities for disjuncture

25   between procedural ethics and situated 'ethics in practice', it has also expanded the meaning

26   of reflexivity from a largely methodological concern to one that also carries important ethical

27   responsibilities (Guillemin and Gillam, 2004).

28

29   **Reflexivity as personal responsibility**

30   In the social sciences, reflexivity – an explicit self-analysis of one's own role in research – has

31   become an expected element of qualitative research. This is particularly the case in

32   contemporary ethnographic work where the researcher can forge prolonged and close

relationships with participants. It is now generally understood that through careful reflection we can start to unpick the tangled subjectivities of researcher and researched and to recognise how one's power, positionality and biography shape the research process and the knowledge we produce (Riley, Schouten and Cahill, 2003; Dean, 2017). Thus, the fundamental relationship involved in the pursuit of reflexivity is one between thought (reflection) and action (reflexive practice) and this has its origins in the philosophy of individualism (May and Perry, 2017). In the case of 'sensitive' research, reflexivity is often presented as a responsible means of negotiating issues such as vulnerability and exploitation, which essentially involves the self-management of *individual* researchers and their potential to 'do harm' via diligent introspection.

Denzin (1997) has suggested that the 'ideal' researcher is '… a morally involved, self-aware, self-reflexive and interacting individual who holds the self personally responsible for the political and ethical consequences of their actions' (1997:277). As important as this is, contemporary researchers are striving to attain this ideal and to meet their ethical responsibilities within a complicated regulatory context proliferating with guidelines, policies and procedures, which direct and delineate what 'good' (correct) research looks like. In our experience, this can feel overwhelming for 'junior' researchers in particular. And so whilst we agree with the many accounts which argue that reflexivity is important - that it is methodologically helpful and constitutes ethical practice (Guillemin and Gillam, 2004) - we want to acknowledge its problematic elements (Riley, Schouten and Cahill, 2003) and to highlight in particular the neglected issue of the various 'costs' of introspection for researchers.

In the section that follows we 'trouble' our own reflexive experiences. Through writing about our own challenges in the examples below, we raise the possibility that cycles of introspection about the 'sensitivity' of one's work as well as what this assumes about a potential to act unethically, exploit vulnerability and cause harm, may ironically engender particular vulnerabilities in us as researchers.

About the research

1 **Our 'sensitive' research projects**

2 Over the last 10 years, we have both conducted ethnographic fieldwork in England about care

3 and relationships towards the end of life. This section describes the projects that gave us the

4 specific experiences we draw on for examples within this paper. Whilst we focus here on two

5 studies carried out at the start of our careers as death researchers, our subsequent research

6 experiences looking at palliative care in medical education, multidisciplinary team working in

7 healthcare settings, online forums for individuals with life-threatening illness, and baby loss

8 and post-mortem, also inform what we have come to describe as 'internalising sensitivity'.

9 Like Smart (2014), we consider sustained involvement in qualitative research as biographically

10 significant for the researcher and our research careers to date have fostered an

11 understanding of the 'fuzziness' of research beginning and endings. In this sense we value

12 Smart's (2014) description of data as research fragments which accumulate over time and

13 acquire the potential to reveal, affect and haunt us in different ways.

14

15 *'Constructing' end-of-life care*

16 Erica's research has focused on how the 'end of life' is constructed, practiced and

17 experienced, from the perspective of policy and policy-makers, those providing professional

18 and informal care, and those who are supposed to be the subject of end of life care. Her

19 largest fieldwork to date on this subject involved observing 50 hours of policy-related events,

20 250 hours of participant-observation in clinical settings, care homes, and disease-related

21 support groups, and 100 interviews with policy-makers, health and social care professionals,

22 and people living with life-limiting illness and/or their partners/family/carers. She also spent

23 up to 14 months regularly visiting people living with life-limiting conditions near the end of

24 life (and their families and health or social care professionals were possible) in their homes

25 and other locations related to their everyday life and care (Borgstrom, 2014). These visits

26 included anything from informal chats, to sharing family meals, to accompanying people on

27 their clinic appointments or visiting them when in the hospital and ranged in the spectrum of

28 participant-observation depending on the context and arrangement with participants.

29 Encounters included witnessing emotional and/or physical distress, sensing family tension,

30 and in some cases, being present shortly before the death of the person. As part of the

31 research design process and ethics committee approval, these kinds of scenarios and

32 'appropriate' responses were explored, including how to ensure participant consent, provide

for researcher safety, and account for the potentially emotionally charged nature of the research. Throughout the research parallel field notes and field diaries were maintained, and combined with regular academic and peer-support supervisions. A reflexive approach was inherent within the project's methodology and was actively used to frame the study's findings. This is evident in the doctoral thesis, where extracts from the field diary were used to introduce each analytical topic.

Family practices and the end of life

The experiences Julie describes in this paper relate to her ethnographic work that explored how everyday family life is pursued when someone in the family has a life-threatening or terminal illness (Ellis, 2010). This study used the concept of family practices (Morgan, 1996) to theorise the mundane and everyday aspects of living as a family nearing the end of life both at home and when staying on a hospice inpatient ward. Julie completed 175 hours of participant-observation at the ward where she took-up the role of a hospice volunteer, chatting with patients and relatives, making drinks, tidying around and assisting at mealtimes. To record her reflections about family life on the ward, Julie kept fieldnotes which integrated observational details, analytical thoughts and emotional and personal responses to spending time with severely ill people and their family members. She also conducted 39 in-depth interviews with relatives from nine different families where one member was living with a life-threatening illness. These were very informal and involved repeat interviews with some family members where circumstances and illness trajectories allowed. Interview participants were recruited via the hospice's day care service which is based in the North of England. Fieldnotes were completed following each interview encounter, recording important contextual information and the researcher's personal feelings, which were reflected upon during analysis. Both interview transcripts and fieldnotes were coded and analysed using a narrative approach to thematic analysis. Like Erica, a reflexive methodological approach was adopted throughout the research process. It featured regularly during formal supervision with Julie's doctoral supervisor. At the time, the personal toll of completing the work was discussed and vulnerabilities, which feature in the example below, could be evoked, although they never felt fully articulated.

1   Our experiences of internalising sensitivity

2 We have chosen the following examples after careful consideration and discussion about how

3 the discourses of 'sensitivity' have impacted upon how we experience our research and how

4 they continue to affect and haunt us in different ways (Smart, 2014). We have shared similar

5 examples previously in conference presentations (with varying receptions), in discussions

6 with colleagues, and in our PhD theses and subsequent publications (Borgstrom and Ellis,

7 2017). However, some of the specific instances we discuss here are making a tentative and

8 somewhat nervous first appearance in print for a wider audience. Tentative because we do

9 not want to suggest that the examples offer comprehensive coverage of the issues we

10 explore, nor do we expect they are particular to us. We offer them here as an invitation to

11 others to share their experiences of living with 'sensitivity' in the various contexts of their

12 work. We are also very aware of how we may have selected certain examples rather than

13 others in an effort to 'protect' ourselves as 'vulnerable researchers' from the risky and

14 exposing nature of reflexive publication (Blackman, 2007; Dean, 2017). With these issues duly

15 acknowledged, the purpose of us offering these examples is to enliven methodological

16 discussion. In doing so we hope to expand theorisations of researcher vulnerability that

17 extend beyond issues of personal safety and emotionality. This enables us to examine how

18 the ethical discourses we operate within might contribute to our own vulnerability as

19 researchers.

20

21 We have selected three examples:

22   - Experience of family bereavement immediately after fieldwork involving end-of-life

23   care

24   - Being alone with a dying person during fieldwork

25   - Writing about 'the mundane' towards the end of life

26 In each of these sections, we write in first-person about our accounts and experiences,

27 sometimes drawing on adapted extracts from our field diaries to demonstrate the visceral

28 and emotional sense of vulnerability as it 'got under our skin'.

29

30 ***Can I just feel it? Family Deaths Filtered***

1 Here we describe how discourses around death studies shape how we view ourselves and our

2 personal responses to death outside periods of formal fieldwork. As ethnographers, we are

3 trained to think about our own everyday experiences as on a continuum with fieldwork, as

4 part of a quest to continuously make the familiar strange. This has enabled us to note and

5 seek to make sense of these occurrences within a framework of 'doing' research. It has also,

6 perhaps, desensitised us to how strange it may be that the discourses that surround the type

7 of work we do have affected our 'non-professional' lives. To illustrate this, Erica reflects on

8 caring for her paternal grandmother, an experience which highlighted the impact of her

9 exposure to the idea that participants in death research are inherently vulnerable.

10

11 Weeks after finishing my fieldwork about end-of-life care in England, I was back in

12 the USA visiting family. Whilst I was there, it was revealed that my paternal

13 grandmother had recently been diagnosed with cancer. She was in the midst of

14 deciding to decline further investigations and treatment. Soon I would visit again and

15 effectively become her 'carer'.

16

17 During this time, I had a desire to separate work from personal life, and an inability to

18 actually do so. Months later, my mother remarked that my grandmother was excited

19 that I could be 'studying her', something I resisted in practice. I wanted to just

20 experience the moments for what they were, not to be making mental fieldnotes. I

21 wanted to have memories that were not categorised or tainted with anthropological

22 theories, analysis, or attempts to generalise from the particular.

23

24 Yet, it was when I was caring for my grandmother, doing the gardening one afternoon

25 that I really connected with my previous fieldwork experiences. As I picked up sticks

26 from the grass, something reverberated through me that made me recall a

27 conversation I had with a man who knew he was dying, a side remark about how much

28 waiting there is in the process of dying. I could begin to understand aspects of what

29 my participants told me that seemed trivial before.

30

31 It was only later that I realised that my desire to separate my personal experience

32 from my fieldwork mode was because I thought I needed to protect something, and

someone – me and my experiences of personal deaths. I had, through the way research is framed in death studies and in healthcare research, seen myself, as a soon-to-be-bereaved grand-daughter, as someone who needed to be protected around the time of death. Someone for whom intrusion – from research – had to be limited. I had projected myself as a 'vulnerable person' because that is how the participants of my research are often portrayed; and I was now in similar circumstance. But without this notion of vulnerability, I did not necessarily feel I was particularly emotionally vulnerable because of being a carer to a dying grandmother. It was because I thought *I should be vulnerable* that caused me to become unsettled.

Moreover, I began to see myself as 'uniquely vulnerable'. Vulnerable both because of the situation (caring for a dying grandmother), but also because of the heightened knowledge I had about death due to my research. I had gained knowledge about death and dying that most people don't have until they experience it first-hand. And I became angered because there was no one to protect me (the grand-daughter) from me (the researcher with knowledge), and I blamed reflexivity for my ability to be critically aware of this dual positionality. Those who knew both my research and personal situations did not view me as 'vulnerable'. In fact, the opposite was often presumed: that if I could 'handle it' professionally, then personal encounters with death would not be particularly difficult.

Reflexivity, although considered a prerequisite of contemporary social science research, can be quite unpredictable (Kress and Frazier-Booth, 2018), and this series of realisations felt unpredictable. This example highlights for us how the discourses of vulnerability and sensitive research that permeate death studies can impact our own personal experiences of death. It also illustrates how being reflexive can heighten this awareness, without necessarily providing an outlet for the emotionality that it engenders. In other contexts, this dual positionality is viewed as potentially productive; for example, in creating more compassionate doctors when the doctor self-identifies as a patient-practitioner (Rowland and Kuper, 2018). Whilst the dual positionality here may have furthered aspects of Erica's analysis, it also had unintended consequences of disturbing the experiences of familial death.

Should I be here? What to do when observing

A common experience in our fieldwork in end-of-life contexts is asking ourselves: should I be here? Should I be witnessing this? On and off throughout our careers we have been fearful of the charge of voyeurism (Hockey, 2007) and what our desire to observe 'vulnerability' in this rather 'extreme' sensitive context might suggest about us as 'moral' individuals. In this section, we provide a particular example from Erica's research where her internal dialogue about whether this was the 'right' thing to do manifested in deeply embodied ways in the field (Okley, 2007). What Erica notes here also echoes experiences that Julie had during her fieldwork when she agonised over if and when it was OK to enter a patient's room on the ward. This was something she too experienced in embodied terms in her discomfort at hanging conspicuously and awkwardly around door frames.

> I found Mable in the care home that she had been discharged to after her rather
> lengthy and unexpected hospital stay. A care worker showed me to her dowdy room,
> where she promptly left me before I had even entered through the doorway. As I
> peered around the doorframe I saw Mable in her bed. I softly announced my arrival
> and made my way to the room's only chair. Sitting down, I explained to Mable what I
> was doing whilst simultaneously unsure of myself. Mable had previously said I could
> visit, even if I found her asleep, but this being the first time, and her body restless, it
> felt odd to be there. I wasn't quite sure how she was doing or what this sleep 'meant'
> – could she be in her last days of life?

> I took out my notebook, like I felt a dutiful anthropologist should, and jotted a few
> lines about the layout of the room and what was going on. The chair I was sat on was
> at the foot of her bed. I realised I couldn't just sit and observe her. I was reminded how
> the university research office joked about how tabloid papers might report on my
> project: 'researcher watched my mother die'. They were worried not just about the
> ethics of the project, but the social and moral response to such a 'sensitive topic'. But,
> at the same time, I was constrained by 'ethical procedures' to 'not doing anything' –
> according to the ethics committee and university research office, I was to observe,
> not to intervene. Yet, what would 'intervening' in this situation look like?

At some point during my visit, I sat on Mable's bed near her legs. I continued to speak softly to her, talking about the flowers and saying things like 'it is okay'. I did not want to wake her. Thinking back, I do not know where those words came from. I lightly touched her, and I recoiled. Not because I did not want to offer the compassion that I associated with the action, but because I questioned it in light of the 'ethics' of doing death research. What right did I have to touch her? What obligation did I have not to? When I visited Mable in the hospital, she often wanted to hold my hand as I listened to her stories. At the time of writing this article, I can still feel the folds of her paper-thin skin in between my fingers as I type.

Recalling such scenarios serves to illustrate how discourses around the sensitive and vulnerable nature of doing research about the end of life makes us question these actions in the field. The actual details of *what it is like* to be alone in the presence of someone who, as it turned out, was in their last few hours of life was not something that was discussed in all the research design and ethical approval processes. Procedural measures covered consent, not how it would feel. The other times Erica had such 'exposures' was in the company of nurses or doctors, serving both a potential model for behaviour but also an additional site of research focus. Being alone with Mable, Erica was left to wonder what she should do whilst in her room and even if it was appropriate for her to be there at all. Was Mable 'too vulnerable' for Erica to be witnessing her toss and turn? And this, in turn, clashed with the rhetoric about 'not being alone' towards the end of life as being an integral part of a good death (Seale, 2004; Temple, 2010). Without Erica in that room, Mable would have been alone, and yet at the same time, Erica felt internally as if she herself was deserted. Left without a guide in how to be. It is an example of how even with detailed ideas about how fieldwork will be conducted, it is not always possible to foresee all encounters (Cohen, 2000; Fischer, 2015). This lack was apparent to Erica in how uncomfortable she was in her body whilst in that room. The seat was not quite right – she could not settle for long, as if she was unconsciously mimicking how Mable tossed in the bed. Sitting on her bed felt simultaneously wrong and right.

1   What this experience also highlights is the concern that researchers – and those who
2   supervise or fund their research – have about the stigma attached to conducting 'sensitive
3   research' and how their methods may be interpreted (Lee, 1993). Reflexivity has enabled us
4   to acknowledge that this fear of stigma influenced the research office's remarks about the
5   project, and in turn affected how Erica made sense of her own actions on the day.
6   Nonetheless, reflexivity cannot mitigate the feelings of stigma, discomfort, and shame which
7   persist long after the fieldwork has ended and continue to make writing about such
8   experiences feel risky (Dean, 2017).
9
10

11   ***Can I publish this? Data and Revealing***
12   In this final example, Julie shares her thoughts about 'the analytical aftermath' of doing
13   research, acknowledging that the post-study period is not readily discussed in terms of how
14   it affects the researcher and the emotional labour it can involve. In this section, we focus on
15   an example of 'chilling'. Chilling is when researchers defer or deliberate about dissemination
16   of research on a particular topic because they await possible hostile reactions (Lee, 1993).
17   The following are notes from Julie's fieldwork diary taken at the time of the study.
18

19   In the car driving home, I felt strange - subdued and numb, but also a little tearful. It
20   made me sad to think about what Malcolm and Tracey [1] are facing and I began to
21   feel troubled about putting the thesis together. I get mixed feelings - sometimes
22   feeling bad for having a numb and detached feeling and not being overwhelmingly
23   burdened by the circumstances I find people facing. Perhaps their ability to just get
24   on and do makes me able to be saddened but not paralysed by distress. But then, I
25   do feel compelled lately to reflect on my own life and the time I have and how I use
26   it... time is passing quickly and studying dying is magnifying the importance of
27   maximising it. I feel so guilty because I imagine I ought to be more committed to the
28   thesis and not have to struggle to sit down and work on it. I'm aware that the sheer
29   enormity of the task is overwhelming - I feel lost for ideas - not sure of what I want to
30   say about any of this. Could this explain the numbness and detachment - the lack of
31   motivation? Of course, feeling indebted to the families who have spoken with me is
32   an added burden - I feel like I'm struggling with getting themes to emerge - I'm

1   'feeling' the 'ordinary' yet specific life worlds of individual families and I am starting

2   to wonder if illness experiences within families are just different and what more can I

3   say than that? If I simply re-tell their stories how am I doing anything they couldn't?

4   Ultimately the work seems trivial... imagining Malcolm's isolation [due to deafness]

5   makes the thesis feel small, like nothing - like it couldn't do anything to touch the

6   magnitude of what that experience must be like - yet the mundane comes in as the

7   everyday world keeps on ticking over. What can I say about this?

8

9 As this extract shows, Julie was troubled by any 'mundanity' in her own approach to, and

10 reflections about, the research. Whilst this suggests a sense of ambivalence about generally

11 being able to get on and not feel emotionally overwhelmed, it also points to difficulties in

12 analytically working out how to make sense of the 'everydayness' in the data. In the process

13 of considering her own emotions, she began to see how she was also struggling to formulate

14 an analytical perspective on how the everyday and the mundane intersected with the more

15 extraordinary and emotional experiences we associate with dying. Assumptions regarding

16 the intensity and drama of death meant that constructing an account that gave voice to the

17 mundane and everyday present in family stories was challenging. This was both analytically

18 and emotionally challenging as Julie felt in danger of trivialising such a 'momentous' issue.

19

20 Against a background of discursive framing which tends to conceptualise dying as fearful,

21 denied and ontologically troubling, it has felt quite challenging and exposing to talk about

22 interpretations of data which foreground the 'everydayness' of dying people's feelings and

23 the ordinariness in their accounts. Whilst it has not been Julie's intention to suggest that

24 living with life-threatening illness is not an extraordinary, emotional and difficult experience,

25 there is a worry that in making a case for the explanatory relevance of the mundane, it might

26 be seen this way by others. Whilst even the most robust researchers might feel anxious about

27 whether the patterns they see in their data and the interpretations they present as 'findings'

28 are accurate, fair and make sense, these worries and crises of confidence feel especially

29 difficult to shake when researching 'emotive' subjects like dying. In other words, discourses

30 around participant vulnerability have heightened our own vulnerability - induced by an ever-

31 present but unhelpfully nebulous awareness of our potential to cause 'harm' – something we

32 carried throughout fieldwork and which persists into the dissemination of our research. Being

reflexive has helped us to be attuned to this potential to cause harm but it has also, particularly in Julie's case, encouraged a level of critical introspection that at times felt almost destructive (personally and professionally). For her it has not always been possible to retain perspective on the limits of what one can feasibly control – particularly at the point of dissemination when control has to be given up to the scrutiny of others. And so, with this last example we seek to show how researcher vulnerabilities can become entangled with and fuelled by a concern to always act 'sensitively' and that this can have a direct impact on managing aspects of the research process.

Discussion

In this paper we have drawn on reflexive examples from our own research to illustrate how discourses of vulnerability, due to our research being 'sensitive', have been internalised and 'gotten under our skin'. These examples illustrate how this internalisation has influenced the way we feel and think about our research and personal experiences. Our discussion of reflexivity illustrates how 'fragments' of research often extend beyond the boundaries and time limits of individual projects, and can continue to 'haunt' us (Smart, 2014). In attending to our own vulnerability, we see the possible limits of current ethical framings of 'sensitive research', and of reflexivity as a methodological tool, where our points are aligned with discussions about the need to do ethics-in-practice rather than be procedural (Pollock, 2012; Sikic Micanovic, Stelko and Sakic, 2019) . Beyond acknowledging this, the purpose of sharing these examples is to generate a space where the limits of reflexivity within sensitive research can be explored.

Firstly, we are not suggesting that reflexivity is not useful – it is often very helpful. We both continue to work reflexively and this paper is an example of that. Reflexivity has also enabled us to make analytical connections through introspection. For example, Julie was able to wrestle with what appeared to be the paradox of the mundane in the extraordinary. And Erica began to understand what participants had told her after going through similar experiences herself, a phenomenon familiar to other anthropologists who have experienced a personal bereavement (Behar, 1996). Reflexivity also enabled us to question our positionality in the field and when collecting data, as illustrated in the second example. This is often the reason

1   cited for why reflexivity is utilised within the social sciences and related disciplines

2   (Kleinsasser, 2010; Abdullah, 2019). However, as evident in ethical discourses about

3   protecting 'vulnerable participants' of 'sensitive research', reflexivity tends to be associated

4   with the idea of protecting participants from harm (Kumar and Cavallaro, 2018).

5

6   Reflexivity is used within social research as a way to mitigate (primarily) participant

7   vulnerability and/or harm caused to participants through their engagement with the

8   researcher and research project. The individual researcher is expected to use a reflexive

9   approach to consider power dynamics, biases, and subjectivities (Pillow, 2003). Therefore

10   the researcher – as a person – is an instrument in the process (Geertz, 1973), and the site

11   for mitigating vulnerability and harm. One 'solution' offered for managing sensitive

12   research, therefore, is to manage the individual researcher via introspection and reflexivity.

13   What has been less explored is how for the individual researcher, this responsibility may be

14   challenging and potentially harmful.

15

16   By drawing on examples that highlighted our own vulnerability, we seek to raise awareness

17   about the limitations of reflexivity in terms of protecting researchers from 'harm'. We have

18   done this by sharing how reflexive practices have amplified our own sense of vulnerability at

19   different times in our lives. While as a research community we are getting better about

20   discussing the emotional implications for the researcher of doing sensitive research, attention

21   is generally on the period when researchers are in the field engaging with participants

22   (Dickson-Swift *et al.*, 2007; Woodthorpe, 2011). Other aspects of the research process – such

23   as producing notes and transcripts, performing detailed analysis, recounting stories for

24   dissemination, or even listening to other researchers as part of peer-support – are also

25   emotionally tiring and pose moral dilemmas (e.g. Evans *et al.*, 2017). It is important to note

26   that often these experiences can be highly individualised, personal and lonely, even in team

27   environments because whilst research teams may sometimes write ethics applications

28   collaboratively, the responsibility for translating these linear narratives into actions (or

29   inactions) in the field lies with individual researchers. At times, as this paper demonstrates,

30   doing research and living with its consequences has felt as if it could be 'harmful' to us as

31   people. That we have begun to consider that *we could be harmed* through the research and

32   reflexive process further indicates the internalising of the vulnerability discourse.

This sense of our own vulnerability resonates with Smart's (2014) suggestion that social researchers can be 'haunted' by living with the fragments of other people's lives. For us experiencing aspects of our research as 'haunting' is rather apt, given that data analysis actually involves 'working with the ghosts' of dead participants (Komaromy, 2005), which have accumulated through our various projects generating a cumulative effect over time. Hearing their voices in recorded material or recalling time spent with them, makes the responsibility of producing an account of their experiences even more overwhelming. Smart (2009) suggests these feelings of responsibility are central to developing a 'sociological conscience' which she has described as the intersection of a researcher's personal life with the practice of doing research. This haunting collides then with an ethical and moral imperative for us to not only produce 'good data' (Kleinsasser, 2010) but to be also ultimately 'good researchers' (Macfarlane, 2010). However, to-date, there appears to be little space within the academic community to comfortably share these experiences.

We are therefore adding a note of caution to the idea that reflexivity can always function to alleviate vulnerability in sensitive research, particularly when experienced by researchers. Specifically, what reflexivity does not always provide is a solution to the 'living with' of our research and the effects of the vulnerability it can engender. By introducing the idea of 'internalising' discourses such as sensitivity and vulnerability we hope to offer a conceptual means for researchers to talk and write about similar difficult feelings in a way that avoids moral judication of the research or the researcher. Whilst our experiences stem from our work in death studies, what we describe has broader implications. It is particularly useful for the growing field of sensitive research, and thinking about the longer-term impacts of conducting research that is 'sensitive'. Being able to discuss how research experiences can indicate internalised sensitivity is useful in enabling us to think critically about research methods, training of researchers, and communities of practice.

Notes

[1] Malcolm and Tracey participate in a series of interviews for Julie's research. They were married and both in their 50s. Malcolm was living with a terminal cancer diagnosis.

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